**NPM 06:** The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life. (CSHCN Survey)

Annual Objective and Performance Data	Tracking Performance Measures (Sec 485 (2(2)(B)(iii) and 486 (a)(2)(A)(iii)						
	2000	2001	2002	2003	2004		
Annual Performance Objective				6.8	7.8		
Annual Indicator			5.8	5.8	5.8		
Numerator			64,727	64,727	64,727		
Denominator			1,116,374	1,116,374	1,116,374		
Is Data Provisional or Final				Final	Final		
	2005	2006	2007	2008	2009		
Annual Performance Objective	7.8	8.0	8.5	9.0	9.5		

#### Notes - 2002

Source: SLAITS CSHCN Survey. <u>Data issues</u>: Maine is the only state that met the NCHS standards for reliability for PM 6; therefore, the 2002 indicator we use is the national average.

#### Notes - 2003

Source: NCHS SLAITS CSHCN module; the data reported in 2002 pre-populated the data for 2003 for this performance measure.

#### Notes - 2004

The data reported in 2004 are pre-populated with the data from 2003 for this performance measure. State data was not robust enough to use; therefore national data is shown. Projections for 2005-2009 are very rough estimates. We expect to have state-level data from the Wisconsin Family Health Survey in time for next year to supplement and adjust projections (if necessary).

## a. Last Year's Accomplishments

The CSHCN Program worked closely with the University of Wisconsin - Waisman Center, the CSHCN Program's Healthy Ready to Work (HRTW) designee. The Waisman Center is one of five Title V funded Regional CSHCN Centers in Wisconsin and uses it's HRTW expertise to provide leadership and technical assistance to the other four Centers. The Waisman CSHCN Center 800 line doubles as the "Statewide Transitions Information and Referral Hotline". The State CSHCN Program and other Regional Centers participate with the Waisman Center in the HRTW Statewide Interagency Transition Consortium. During 2004, 477 youth with special health care needs (YSHCN) received information and/or training provided or facilitated by the Waisman HRTW Project working through the CSHCN Program and/or the five Program funded Regional CSHCN Centers.

#### 1. Outreach--Population Based Service--CSHCN

The CSHCN Program co-sponsored the annual Circles of Life Conference for Wisconsin parents and providers where the HRTW Project funded the concurrent Gathering of Youth. Calls to Wisconsin First Step (CSHCN/Birth -3 resource hotline) with questions on youth with special health care needs transition resources or procedures are referred to the Waisman Center HRTW Project hotline and website and HRTW coordinates a Wisconsin Transition list serve. Centers assist in data gathering by documenting transition services they provide as well as needs that go unmet.

### 2. Training--Infrastructure Building Services--CSHCN

HRTW and CSHCN Centers conducted a series of trainings for high school students, their teachers and parents regarding Transition IEP's. Youth, parents, educators and other community service providers received training on the "PATH" person--centered self-determination process. HRTW provided nine workshops to parents/providers on supporting youth in their health care decision making. CSHCN Program established a Wisconsin Medical Home Learning Collaborative with 9 primary care practices. As part of that Collaborative the Learning Session 3 focused on the issues of transitions. HRTW provided participating pediatric practices with expertise and insights while learning what information is needed by doctors to assist YSHCN in transitioning to adult providers. Each practice received transition specific resource packets and technical assistance.

## 3. State Partnership Building--Infrastructure Building Services--CSHCN

CSHCN Program designated the Waisman Center HRTW Project as the state applicant for the Champions for Progress Incentive Grant. This grant funded an initiative designed to learn from youth what they need for successful transitioning. Information learned from "Youth on Health" will help guide the development of a CSHCN Youth Advisory Council.

Activities		Pyramid Level of Service				
Activities	DHC	ES	<b>PBS</b>	IB		
1.	Outreach			$\mathbf{X}$		
2.	Training		$\mathbf{X}$			
3.	State Partnership Building				X	

## b. Current Activities

# 1. Training and Outreach--Training Infrastructure Building Services and Outreach Population Based Service--CSHCN

Each Regional Center provides at least one transition training for youth, parents, and/or service providers. Outreach in the Southeast Region includes "community connectors" who are available to provide more in-depth applications of person-centered life planning and asset based community development models for Latino communities. All Centers provide training related to guardianship issues. HRTW, Department of Public Instruction (DPI), and Division of Vocational Rehabilitation (DVR) continue to provide funding and resources for week-long "Transition Camp" that provides disabled teens with an opportunity to be away from home, with peers and have fun as they learn about transitioning. DPI's State Improvement Grant (SIG) for Transition funded four 8-week courses developed by HRTW that teaches youth with disabilities the concepts of personal safety at home, at work, and in public.

#### 2. State Partnership Building--Infrastructure Building Services--CSHCN

HRTW Project worked with Social Security Administration (SSA) and the state Division Disabilities and Elder Services (DDES) to include transition questions in a new functional screen for children with long-term care needs. The CSHCN Program and Waisman Center HRTW partnered with funding received from "Champions for Progress" grant to initiate "Youth on Health". This process included four Collaborative Problem Solving (CPS) sessions. Three of the sessions included youth from across the state, and one session was held at a Hispanic community center in inner city Milwaukee with all participants primarily Spanish speakers. Some of what was learned includes the report by many YSHCN participants that they have thus far learned to take little responsibility for managing their health care. Thirteen of the 32 youth participating

reported having had no discussion of, nor plan for transitioning to adult health care. Several participants reported having difficulty getting listened to and/or having their special needs appropriately addressed in emergency room and hospital care settings. Some of the additional concerns expressed by these youth included insurance coverage issues and the lack of information about heath care. Information from "Youth on Health" CPS sessions will be used in the Five Year Title V Needs Assessment and Block Grant Application.

## c. Plan for the Coming Year

## 1. State Partnership Building--Infrastructure Building Services--CSHCN

Transitions for YSHCN has been identified as a major focus for the CSHCN Program in the newly MCHB funded Wisconsin Integrated System for Communities Initiative (WISC-I). Anticipating the conclusion of HRTW in June 2005 the CSHCN Program will continue to support the Transition Consortium and the transition list serve through a contract with the Waisman Center. Consortium members will be invited to participate with the CSHCN Program in a comprehensive strategic action planning process with the goal of assuring healthy transitions for Wisconsin's CYSHCN. In addition, the CSHCN Program with the Waisman Center will establish a Youth Advisory Council (YAC) based on the information learned from HRTW and the Champions grant. The Regional CSHCN Centers will continue to support transition activities at the local and regional level along with continued participation on the Consortium. As part of implementation of WISC-I the CSHCN Program will plan a Medical Home Learning Collaborative with youth, families, tertiary care providers, administrators, and primary care providers that will look at transition from pediatric to adult care services. The two major pediatric tertiary centers have agreed to participate. The anticipated outcome as part of WISC-I is the establishment of mechanisms to support transitions at the tertiary care level.

# 2. Outreach and Training--Training Infrastructure Building Services and Outreach Population Based Service--CSHCN

The CSHCN Program in partnership with the Waisman Center and other Regional CSHCN Centers will disseminate the many training and technical assistance materials developed by the HRTW over its four years of operation. Included are: curriculum for community safety awareness and empowerment, a guide for involving youth with disabilities in organization activities, a training packet for youth and/or families on health care awareness/advocacy, videos on legal decision-making at age 18, successful transition stories, and topic specific fact sheets. For example, training will be conducted for the over 100 school districts regarding the safety curriculum. Regional Centers will continue to provide technical assistance to local communities and medical home providers.

Wisconsin's CSHCN Program through the continuation of the Transition Consortium, anticipated continuation of the regional CSHCN center concept, and establishment of the YAC will continue collaborating with families, youth and other transition stakeholders in training and public awareness activities as well as planning and service design.